

My Pulsatile Tinnitus (PT) Story to Date

February. On February 04, 2018, I had a whiplash accident while climbing a local mountain; the full story is here: <http://hwstock.org/muddy18/#RestofStory>. Immediately after the accident, my SCM (on neck) and trapezius muscles were very sore, especially on the left side of my head and up near my skull. I had a freak cerebellar stroke 16 years ago, from a neck injury, so my first concern was not to have another. I had a cervical X-ray that showed nothing unusual.

(I'm almost 64, but I have good aerobic capacity. Last I was given a test, body fat was in the lowest 1/2% for my age. At the time of the accident I could do 22 good chin-ups in a set, so I was also fairly strong.)

Sixteen days later, I had a dental appointment, where my head/neck was positioned over the back dental chair for hours. That night the PT started in my LEFT ear; at first I just thought it was the cat snoring. When I patted the cat and she woke up, I realized this was something else. I fully expected this was something temporary related to my accident; but it got worse the next few days, and I googled the symptoms, almost immediately found **whooshers.com** (this site sped up my learning, and gave me valuable pointers). I particularly remember reading that PT rarely goes away on its own. That was a Saturday, so I went to an urgent care clinic. They were sympathetic, and believed me, but wrote it off as Eustachian tube dysfunction, which I've learned is a basket term.

March. My PT rarely was intense when I was upright, but I would hear it during strenuous exercise, like climbing mountains. Usually, it was silent unless I were lying down to sleep.

Next I went to the ENT, who believed me, but thought the PT might be a result of my TMJ issues, exacerbated by the accident. He made sure I had no ear injuries or infections, and readily admitted Las Vegas had no real expertise in this issue. He did order an MRI and MRA, to rule out the bad stuff, like a tumor or arterial dissection. I knew by now that vascular PT was usually venous, so the MRA would not be a really big help.

The poor communication among the ENT's secretary and the radiology office resulted in the MRA not getting done (they did just the MRI). I had to make a lot of calls to get another shot at the MRA. I have a piece of non-magnetic metal in my body, which has been tested safe to 3 Tesla; but the CYA attitude of radiology centers mean that I always get stuck in the older 1.5 Tesla machines, and get crappier test results. I bring copies of the newer peer-reviewed studies on safety, but they will only take the original FDA approval from 2001, when few 3 Tesla

machines existed. This decision always gets made by an anonymous technician; the higher-grade radiological technicians in the MRI room often tell me the 1.5 T restriction is silly. But we live in a world of clueless gatekeepers. Las Vegas is where radiology goes to die. I finally convinced them that the MRA was requested, and it was done about 2 weeks later.

Both initial MRI and MRA were deemed “normal” by the radiologist. I had learned to read MRAs long ago, because of the stroke and my scientific background. I was looking at the MRA, and notice my right-side PICA (posterior inferior cerebellar artery) was missing; this doesn’t surprise me, since it was occluded in my stroke. But the radiologist’s findings were that the cerebellar arteries were “normal.” That told me right away that the radiologist’s impressions of the MRA were not a strong indication of anything, since he failed to notice that I was missing an important artery.

About this time, late March, the PT was making it hard to sleep soundly, and was getting louder. I sampled lots of earbuds and mini MP3 players before I hit on something that would play brown noise just loud enough to drown out the PT. I found that brown noises, available as apps on a smart device, or as MP3 files, are not equal. The basic form of the spectrum of dB vs. frequency may be the same, but the random variations placed on top of that are not specified. Some brown noise was irritating, but I found one MP3 file that reminded me of sleeping near a mountain stream this MP3 cost a few \$. (I found the noise produced by free apps had a short cycle time, which I could perceive as an annoying “regular” sound.) It took a long time to find earbuds meant for sleep, that were small enough and would not interfere with the occasional side sleep. I also noted that in the rare times I slept on my right side, the PT seemed to transfer to my RIGHT ear; this seemed quite odd, but would seem significant... to some of us... 5 months later.

About this time, I also discovered an unusual aspect of my PT. Many folks reported they could stop the whooshing by pressing on a spot right behind the ear; often this was associated with a suspected dAVF of the sigmoid sinus. The only pressure point I could find was near the base on my skull, more to the back, right between the upper SCM and trap muscles, and over the occipital vein and artery. And pressure made the PT get WORSE; I could now bring it on, which would surely be more useful if I went to a doctor’s appointment, because they were not about to let me lie down to sleep for the exam. When I released the pressure, the PT went nearly silent for a minute or so.

My next scheduled ENT appointment was in the afternoon in late March. My head was a bit addled, but I decided to do a quick “scramble” in some nearby mountains, partly to lift my

spirits. Iffy sleep had softened my normal caution, and I picked an extremely difficult route, which most folks would have done with rock-climbing gear. I dislocated my right shoulder; after trying unsuccessfully to reset it on the spot, I climbed down with one arm, walked out and picked up my wife, so we could go to the ER. Because the respiratory specialist wouldn't answer a page, I sat there in great pain for more than 4 hours, until my wife signed a consent form to let them sedate me and proceed with the reduction (which took 5 minutes). One of the amusing things: I wished that the traumatic experience would somehow fix the PT; it didn't.

April. The shoulder dislocation sidetracked my PT concerns for 40 days, as I went through shoulder surgery and physical therapy.

Early in April, I asked my PCP if he would refer me to the UCSF PT clinic. He agreed, and got the MRI requirements from Dr. Amans. My PCP didn't understand what the requirements meant, so he called a med school bud who ran a local radiology lab. I had some misgivings, because that lab had made some really stupid mistakes with my radiology in the past, but now my PCP would cc every request to his bud. At first I thought friendship would help, but it turned out to be problematical, because the radiologist really wasn't up on PT.

May. My experiences with that new radiology lab were bumpy; once again the gatekeeper technicians were very ornery, no matter how polite I was, and made snap judgements. The IT and records system at the lab were inscrutable. The folks who accessed the records refused to believe I had an MRI there in 2012, with the same body metal, and I had to push impatient staff till they found the record. They required I go across town to talk to them directly, and I patiently sat across from the technologist for a half hour until she finally found the record. Then the technicians refused to take the FDA approval information, because I couldn't supply a model number; there was no model number as indicated on the official FDA form. The receptionist pointed out that my prior MRI approval there trumped the "number" requirement, and the technicians grudgingly accepted.

I got the MRI and MA done per UCSF requests, but in a lower-strength older machine. The machine shook so violently that my head was rocking back and forth, and the results were a bit fuzzy. They were also supposed to do an MRA with contrast and MRV of my head and neck; but only scheduled the neck part (for 3 days following, because of restrictions on how often one can receive Gd contrast). This puzzled me, as my PCP had asked me what I wanted done, and I had been very specific about requesting head and neck for contrast MRA/MRV. However, I looked at a Xerox of his submittal and the instructions could be taken to mean he wanted the MRA/MRV with contrast of just the neck, because of the way he structured the sentence. The

technicians said their interpretation of the form was what counted, so I got the MRA/MRV of my neck only. I made three attempts to get a rescheduling through my PCP; I even sent his office an example of how the form should be filled, but it fell through the cracks. Later they acknowledged receiving the form, and admitted nothing had been done.

I got the MRA/MRV with contrast DICOM results back about May 20. At that time, the radiologist's impressions had not been entered into the system, so I looked at the DICOM files myself. Fortunately, "neck" MRV included most of my cerebellum. I was startled when the MRV showed the slug of gadolinium tracer went almost exclusively through my RIGHT transverse and sigmoid sinuses; it was as if my left transverse sinus were not there (spoiler: it wasn't). The left jugular appeared to be wimpy. I figured I must be reading the MRV wrong, so I'd wait for the radiologist's impressions. (I found out just last week that the radiologist's impressions did mention the missing left transverse sinus briefly, but made no mention of the jugular asymmetry.) My PCP's med school bud called him and assured him there was nothing really unusual in the studies, and my PCP called me to relay that information.

The eventual outcome of this exchange was that my atretic left sinus, and jugular insufficiency, was missed. Even though I uploaded the MRV study to UCSF, the label in the DICOM files was just "MRA neck," and one had to burrow into the electronic files to realize it really included a relevant MRV. As near as I can tell, the folks at UCSF never saw the study, and didn't realize that I was missing the left sinus, and had a nearly closed left jugular... till the angiogram on the day of my operation.

I was finally called by UCSF to schedule, in late May 2018. The back-and-forth with my PCP had taken a month, and by now, the first clinic opening was in late July. I told them I would be very flexible and take any cancellation, and got an appointment for June 18. My expectations for the clinic were very low; I just figured this was a condition I'd accept.

June. I was pleasantly surprised when I had my UCSF appointments, an hour with Dr Meisel, and an hour with Dr Amans. Dr Meisel was thorough, and didn't talk down to me. I showed him where I could control the pulsing, and he put an amplified stethoscope over that spot, heard the pulsing, and even put the earpieces in my ears so I could hear as well. (I made my own amplified stethoscope two months before, and recorded the bruit, but the recording was poor.)

Dr Amans was also amiable. I told him about my stroke, and how it was a new baseline (getting used to partial paralysis and the other limits), and ventured that PT would just be another baseline I would have to accept. He said, "no, this is going to go away," and showed me (on the

MRI) where he thought the dAVF was, in the marginal sinus. As we found out later, he was at least partly correct. He viewed this as a fairly low-risk dAVF, thinking he would probably approach from the venous side, up the left jugular. For a moment my brain flashed to my view of the MRV, which seemed to show an occluded jugular, but I was quickly distracted. After all that radiology had been sent to UCSF. After the appointment, I remembered this comment from one of Dr. Amans patients: “No one could read the MRI the way Dr. Amans could,” (<https://radiology.ucsf.edu/blog/pulsatile-tinnitus-one-patient%E2%80%99s-quest-endominous-ringing-her-ear>). I believe that’s true, as long as he gets the info. I have great respect for the UCSF doctors.

Almost immediately on return, I tried to schedule an operation appointment; the best I could do was two months away, on August 21. After all, we thought this was a low-risk dAVF. I had a wedding to attend across the country in the next few days, so I was preoccupied.

At the end of June, I went on a solo, trailless climb of a nearby 11,000’ mountain. I had bad vertigo, so I intentionally picked a route where I could use my hands on the rocks to steady myself. Near the top, I had visual auras, which reminded me of my stroke; so I quickly chewed several aspirin. I was fine going back downhill on an old trail.

July-August. I would go on 6 more gnarly mountain trips in the next 6 weeks; always careful to get my balance back by walking on parking lot lines before I started the trip. I also took some hikes with a friend who had recently suffered brain damage in a mountaineering accident; I thought I might ask her to return the favor someday.

Five weeks before my trip to UCSF, my PT was nearly silent, and the vertigo was gone. However, I saw many comments from people whose PT went away for as long as 7 months, only to return. One week before the trip, the PT came back; I was able to sleep on my right shoulder for the first time in months, and once again noticed a weaker pulsing in my RIGHT ear, but only when I slept on that side.

August. Finally it was time to fly to UCSF. I had arranged 5 nights at the Stanyan Park hotel in San Francisco, a short walk from the hospital, and my wife came out with me. (If you are going to make hotel reservations for SF in summer, you won’t get much choice unless you make them at least a month ahead.)

August 20. The day before the angio/possible operation, I went to several medical appointments. There was concern about my slow heart (43 BPS); normally, people just look at

my legs and ask me, “do you run?” and chalk up the low rate to exercise. I have never had difficulties with anesthesia, but the slow heart always causes momentary concern.

Next, I met with Dr. Coplan. He went through the plans. I mentioned the occasional bilateral PT, and this disturbed him, as they were thinking “left side.” He mentioned that he would pass on that information, but I don’t know if he ever did. As I was talking to Dr. Coplan, I noticed a photograph on the wall, of a person standing in front of Ana Dablam in the Himalayas; the caption read, “Thanks to Dr. Amans and the surgical team for making this possible” – so they understood the strong drive to get back to the mountains.

When I got back to the hotel for the night before the operation, I got a phone call from the anesthesiologist, saying the record (faxed by my PCP 4 months before) showed I had a positive (meaning problem) stress test. They would not operate if this matter were not cleared up. The records said I was a female; my wife has the same PCP, and has once had a positive stress test (later proven to be nothing). My immediate response was that the PCP’s secretary had screwed up, mislabeling the file. Once more, the gatekeepers made a serious mistake. My last night was anything but low-stress, as I made some desperate calls, and managed to get my PCP on the way back from a funeral. It wasn’t till the next morning that the error was cleared.

August 21. So the next day my wife and I woke up, still not sure if there would be an operation, and trudged up the hill to the hospital. It wasn’t till I was prepped for surgery that I was told the incorrect report had been cleared up by my PCP. I went to sleep expecting a low-risk operation, probably with a transvenous closure, after the angiogram pinpointed the dAVF location in the marginal sinus.

I woke up 7.5 hours later, to be told I had a high-risk, 6.5 hour operation. I was asked questions to determine my neurologic state, and was pretty sharp. But I had an enormous headache on the left side. I heard a nurse saying, “notice that smell? That’s the Onyx.” Whoa, this was supposed to be a platinum-coil closure. Then I heard someone say that they had to use 7 coils. I spent the night in the ICU, which was incredibly noisy. My wife slept on a chair nearby, we both got maybe 2 hours of constantly interrupted snoozing.

August 22. The next morn the surgical team came by and told me about the difficulty, and how they had to go through the arterial side. They started to explain about Onyx, using very simple words, and said the smell (which I never noticed) came from something in Onyx... to which I said “the DMSO, used to dissolve the ethylene vinyl alcohol?” The head neurologist laughed and stopped assuming I couldn’t understand what he was saying.

Dr. Amans showed up shortly and explained more details; he encouraged me to get the DVRs with the DICOM files. They had intended to go in through the venous side, but because they went in through the arterial side, they used Onyx, the plastic-like copolymer with tantalum powder. All the platinum coils were used to close a fistula they inadvertently created, and went into a meningeal vein (I didn't realize that till I looked at the radiology). He thought the atresia of the left sinuses, and the wimpiness of the left jugular – which scuttled their plans for a venous approach – were due to thrombotic events; I now strongly question that, having seen their CT scan from the day before, but Dr Amans hadn't had that benefit at the time. (I lack a “notch sign” in the skull on left side, implying the atresia is from birth.)

I got to leave that afternoon, back for the hotel. That night my PT was bilateral and disturbing; I slept by using my mp3 with brown noise on high.

August 23. The next morn I called with the only phone number I had – for Dr. Meisel – and asked if I should be disturbed by the noise and the bilateral aspect. The call was never answered, as near I can tell. My balance was somewhat better the next day. After I practiced walking in the hotel hallway for 30 minutes, my wife and I were able to walk up to the hospital and pick up the DICOM DVDs of the radiology, along with the report on the surgery. I realized that while they thought the actual dAVF was in the sigmoid sinus, they really didn't know; they had done many repeated squirts of iodine contrast fluid, and when they saw a “too-fast” filling of intra-cranial veins, they closed off the small artery that was causing the rapid transport. There were engorged sections of the marginal sinus and posterior condylar vein, so there might be some “cross-talk” between left and right sides, that might explain the occasional bilateral PT. I have yet to hear an opinion on this matter. At the end of the surgery, they did one last squirt with contrast fluid, and saw very little fast transfer to the venous system.

August 24. The next day we flew back to Vegas. There was an 8-hour delay in our flight, so I got to spend a lot of time on practicing my balance. I did get an automated call from the hospital, which I answered totally by multiple presses of the 1 and 2 buttons. I took a UCSF web survey a day later, and was asked if the follow-up call was polite and concerned; it was as polite and concerned as an automated, inhuman call can be.

August 25-30. The six days we have been back in Vegas, I've had 3 nights with PT, and 3 that were silent; the most silent was last night, but I'm not assuming anything yet. I've had a near-constant low grade headache in the front, but don't feel I need anything stronger than acetaminophen, and I'm taking that at less than ½ the prescribed amount. My restrictions were

few; most notably, I was supposed to avoid excursions in blood pressure for an unspecified time as my brain was “sealing.”

A day after the supposed end of my lifting restrictions, our neighbor, who has cancer and is on chemotherapy, called to say she was going to an appointment and couldn't open her garage door. The problem was that the spring was broken, and the door was off-kilter and jammed in the track, but I couldn't see that in the dark. I tried mightily to raise the door, and realized I wasn't doing my brain any favors with the sudden spike in BP. In an hour the PT came on as I was sitting down, and that night was another mp3 player, brown noise night.

August 31- Sept 5. My PT disappeared, but I still had slight headaches and a sense of not being totally aware, and was somewhat unsteady on my feet. Once I had a sudden sense of vertigo while cooking dinner; seconds before, I had a strong sense that I couldn't sync my eyes. I have had diplopia almost from birth, as my head was crushed by forceps, and my right eye socket points slightly down. Usually I can ignore the input from one eye, so my brain doesn't get confused and try to fuse the images. It was not normal vertigo; I could close my eyes and balance on one foot, but when walking, I had a strong sense I was leaning to the left. That balance problem took 12 hours to resolve.

Rest of September and October. A friend arranged several hikes, and that helped restore my confidence, though there were odd moments. Sept. 9, we went to about 8500' and climbed down, then up a small peak, through brush and rough terrain; I felt only the slightest lack of confidence, and surprised her by setting a fairly fast pace. We did another hike at lower elevation a few days later, and my balance was good enough to show her how to use a “body stem” technique to climb up a dry waterfall. Soon we went on a hike/climb to 11300'; while I was in good condition, I definitely felt worse at this altitude, like I were outside my body, watching at times, as I climbed over cliffs. For my birthday, she wanted to climb over Charleston Peak, which got us near 12000'. On the way up (at 10,800') there was a stretch when I was simply walking on a trail and my vision split, and I had a migrainous aura (without the headache). Again, I felt slightly strange, and I was not quite there. I decided the way my eyes were failing to focus was exacerbating the problem, so I took a shortcut over the cliffs to the summit, and the problem went away within minutes. That was a 17-mile day with 5000' of accumulated elevation gain. I went on two more high altitude hikes, with no issues, but for the next 4 weeks stayed at lower elevations; my balance seemed quite good (picture below).

Bridge Mt -- blue is route



Summit -- my balance is better



On October 29, we were going on a repeat of the loop over Charleston Peak, 17 miles, 5000' accumulated gain, starting a bit late in the morning (10:30AM). The other 4 folks were in good condition, and had all been at altitude recently; all of them run ultramarathons. It was cold and I had to force myself to drink; there was ice and snow on the top of the peak.



I hadn't been at altitude for at least 3 weeks, and felt a bit sluggish as we started. The pace was brisk. At the same elevation (~10800'), same trail, where I had an aura and diplopia in September, I had them again. This time there were lots of conversations, and I noticed they were discussing places whose names seemed familiar, but the actual location was suddenly unfamiliar to me. I checked my ability to do math in my head, and I was intellectually sharp. But when asked a question, I struggled to answer in a way that didn't seem like gibberish. I knew what I wanted to say, in terms of an idea, but I had "transient expressive aphasia." This condition is well-known for people at high altitudes, but not usually reported for elevations below 13,000'. In 20 minutes, most of the aura and aphasia had passed, but I still had diplopia, and was having a hard time with all the conversations. So once again I opted to take a "short-cut" up the cliffs, and felt better almost immediately. I still had snow, but my route had less

than the trail, and I beat the other folks to the summit. I had no aphasia when they arrived, and the rest of the trip was uneventful.

When I got home, I dutifully detailed what had happened, and sent a "status report" to UCSF, asking if the two episodes of aphasia were significant. I was surprised when they answered that next afternoon, asking me to come in for an early appointment. Dr Amans thought there was a 50/50 chance the embolization had not taken completely, and once more blood was refluxing into the cortical veins.

My heart sank, but I made preparations to be in San Francisco Nov 15 for an MRI and pre-surgery bloodwork, then Nov 16 for angio/surgery. I distracted myself as much as I could, and went on many aggressive hikes/climbs in the weeks before. One week before my surgery, I took a friend on a trip over 10 small but rugged peaks in a day, using a rope 4 times.

Nov 15-16... *The resolution?* I hope this is the last dAVF part of the story! My wife and I flew to San Francisco on Nov 14, and I had my presurgery tests on Nov 15. I went under anesthesia early on Nov 16.

I awoke in recovery just 2 hours later; there was no need for another embolization; all was fine. I wouldn't even have to come back for the 6-month recheck, unless something unusual happened. This time there was just a slight headache, and a few other annoying side effects; apparently, I bit hard on the bite block as I came out of anesthesia, and damaged a tooth, which is sore to this day, 2 weeks later.

I still have occasional low-level pulsing, sounding more like a soft heartbeat, in my left ear if I lie on my left side for a few hours. I still expect the "other shoe to drop," but not as much as after the August surgery.

Update: January 2019. So far all is well.

Update: May 2021. It turned out that much of my left peripheral vision was destroyed, either by the initial injury, or by the forced embolization of my middle meningeal artery. I have had scintillating scintomas (fortification spectra, visual auras), which limited my driving to less than 150 miles per day. These scintomas would break up my vision, and I learned how to deal with them while climbing, but not while driving. Touch wood, I have not had one for a few months, and have driven up to 250 miles in a day.

The Big Obstacle for Me: Distrust of Surgeons and Radiologists

One of my biggest obstacles has been my deep distrust of surgeons. Last year I had two botched kidney stone operations, and had to get my PCP to order a renal system CT with contrast, STAT. Otherwise the urology office wanted me to wait at least a month, sure that I was just imagining things, like the gripping pain. My PCP had known me for 19 years, knew the masochistic stuff I did for a hobby, knew my PhD thesis at MIT had involved radiochemistry, and knew I wasn't making this up. The CT revealed that they had missed the biggest stone, and the chastened urologist operated the next day.

When I was 22, I had a totally unneeded ureter re-implantment, by a method that was actually proscribed in a few years for anyone over the age of 12. I was told that I would lose a kidney and possibly die, if I didn't have the operation; the surgeon was insistent that I sign the consent paper RIGHT NOW.

I was naïve, and assumed that surgeons were scientists. The medical world has gotten a lot better since then, but back then it was full of surgeons who really wanted to operate on healthy people with good insurance. The surgeons kept ordering more and more radiology, making the conditions more and more extreme, till they finally got the answer they wanted. I was in the hospital for over 2 weeks. After the operation, when there was no change in the IVPs, the surgeon just shrugged it off, and magically found that a ureter was being partly strangled by a vein, that's why my right kidney looked bad to them... but there was no need for more action. The silliness of this operation, which had a bad impact on my life, was not lost on urologists I saw in future years.